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From the Executive Director: Money Talks: Challenging the Status Quo of Breast Cancer

By Karuna Jaggar, BCAction Executive Director

February was a big month for me both personally and professionally. I celebrated my one year anniversary with Breast Cancer Action. I travelled to my alma mata to celebrate Barbara Brenner as she received her Smith College Medal for breast cancer activism. While there I caught an early screening of the film *Pink Ribbons Inc.* And because we can't ignore the pink elephant in the room, like the rest of you, I was angry and disappointed by Komen's defunding of Planned Parenthood.You can read some of my comments here.

Komen's decision to defund Planned Parenthood rightly outraged many women and men across the United States and fueled headlines questioning the status quo of breast cancer fundraising and funding, let alone what it said about how Komen prioritizes (or not) women's health in general. Much of the coverage replicated tired and uncritical narratives about screening that did little to address the root issues of this epidemic. I was glad to see amid this media maelstrom, several important voices raising critical challenges to the status quo in breast cancer. Susan Love, Peggy Orenstein, and Christie Aschwanden published excellent pieces calling attention to the real dangers of promoting screening over prevention and the need to fully consider the number of ways in which breast cancer is held hostage by corporate interests. Heartened though I was to read their pieces, I know that unless there is some dramatic intervention this October the world will be littered again with pink noise and distractions.

We need organizations like Komen to redirect their focus away from the distraction of "shop for the cure" and the oversimplification of "early detection saves lives" because maintaining the status quo is literally costing us lives. Too many amazing women are dying. Breast Cancer Action lost a great friend and colleague when Rachel Cheetham Moro died in January. Personally, I deeply feel the loss of a sharp intellect and strong voice when Wave Geber died a few months earlier. I admire both women immensely. Their deaths, along with the tens of thousands of other women who have died in recent months,are a tremendous loss to the world and an urgent reminder that behind

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mortality statistics real women — friends, lovers, mothers, sisters — are dying from this terrible disease.

The recent Komen debacle once again shone a powerful spotlight on the most important issues that can finally propel us past the status quo in breast cancer: transparency and accountability. We must push for the highest standards in both from all organizations who claim to work on behalf of women with this disease. We must continue to follow the money and recognize that the source of a breast cancer organization's funding always affects its policies, priorities, solutions, and agendas—and yes its grant recipients too. We are very clear about why the status quo exists: most breast cancer organizations, both large and small, receive significant funding from pharmaceutical manufacturers and other corporations that profit from or contribute to this disease

It's been one year since the deeply flawed and profoundly influential *Citizens United* decision declaring corporations to be persons. Nothing better exemplifies the truism that "money talks." Money talks in every aspect of our lives—elections, classrooms, board rooms and even bedrooms,. And breast cancer is no different when money talks in doctors offices, research labs, public policy and regulatory agencies.

Corporate influence has resulted in the overemphasis on mammography as *the*solution to the terrible death toll. The dollars created by pink philanthropy distracts attention away from the huge role corporations play in releasing toxic chemicals into our daily environment and bodies. Prevention studies sponsored by corporate dollars that focus on women's individual behavior (drink less wine, lose weight, have babies early) fail to address the root causes of this disease because the root causes of this disease are inextricably connected to corporate practices and profit cycles.

The new feature film *Pink Ribbons, Inc.*, in which breast cancer activist and former BCAction executive director Barbara Brenner plays a powerful role, opened at U.S. film festivals last month. I can't think of a more timely moment to shine a hefty spotlight on the status quo of breast cancer. The documentary, which the Toronto Film Festival called "powerful and incendiary," pulls back the pink curtain on why we aren't making progress in ending this epidemic.

This movie is a potential game-changer, showing just how much the shiny pink status quo has cost us — and how little we've gained from it. But change won't happen by itself. Watch the documentary. And take a moment, if you haven't already, to download our new (and free!) Think Before You Pink Toolkit. Share a link to the toolkit with 10 other people. Leave a copy at your local clinic, coffee shop, school, break room and anywhere you see pink materials. Help us build our numbers. We have a huge opportunity while this issue remains on everyone's mind. Pulling back the pink curtain is the first step. The reality is action speaks louder than pink. The world is listening

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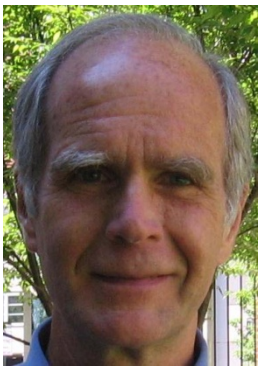
and it's time to put the power of change into the hands of everyone we know because then, together, we can and must change the status quo.

Scientific Uncertainty Is No Excuse for Failing to Protect Public Health

By Ted Schettler, MD, MPH
Science Director, Science and Environmental Health Network



The origins of breast cancer are complex. Many different pathways incorporating individual, societal, and cultural variables lead to this disease. Risk factors for pre- and post-menopausal breast cancers differ. The biology of breast cancers varies, often dramatically. But our understanding of this complexity is rapidly growing thanks to laboratory and epidemiologic research. We've learned that critical events affecting breast cancer risk begin early — during fetal development and continuing through puberty, adolescence, and adulthood. Throughout life, the timing, duration, and combinations of environmental exposures, along with age at first menstruation, timing and number of pregnancies, and activity levels, body size, among other variables, influence breast cancer risk—but not in the same ways for all kinds of breast cancer. In many respects this collection of interacting biologic, behavioral, environmental, and societal variables resembles a complex ecosystem, woven together over time, creating system conditions that sustain health or give rise to disease.

The good news is that this growing understanding supports new opportunities for breast cancer prevention, although the complexity makes clear that, to be successful, we will need to act with less than perfect information. Demonstrating a causal relationship between critical events during fetal development or puberty and breast cancer in adulthood is far easier in laboratory animals than humans. For example, increased breast cancer risk in women after they were exposed to diethylstilbestrol (DES) in utero has only recently become more solidly established — decades after its use during pregnancy was thankfully terminated for other reasons. This illustrates a core public policy dilemma. If we decide to wait for proof of a causal relationship in humans before addressing a risk factor for a complex disease like breast cancer, we will miss opportunities to prevent additional suffering. At the same time, we also need to consider the consequences of mitigating exposures that turn out not to be causally linked to the disease. It comes down to these questions: What is the weight of evidence? Who bears the burden of proof? When do we know enough to

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act? What kind of mistakes are we willing to make? What are the consequences and to whom? What are the alternatives? Who should decide?

Radiation raises the risk of breast cancer, particularly when exposures occur at a younger age. Alcohol use, smoking, and some pharmaceuticals also add to the risk. But the role of most environmental chemicals and contaminants is uncertain and poorly studied, particularly as they interact with other established risk factors mentioned above.

Several chemicals have been causally linked to breast cancer in women, including ethylene oxide, benzene, and 1, 3-butadiene. Plausible, although somewhat less extensive evidence, adds polychlorinated biphenyls, some polycyclic aromatic hydrocarbons, and additional solvents to the list. But the effects of most environmental chemicals have never been studied in women who are exposed occupationally, from consumer products, or general environmental contamination. Instead, much of the limited amount that we do know comes from laboratory animal studies.

Animal studies are generally accepted as being predictive of responses in humans although there is some disagreement about the relevance of high-dose studies for people exposed at lower levels. In 2007 scientists from Silent Spring Institute, a research organization studying the environment and breast cancer, published in the journal Cancer the results of a literature search identifying 216 chemicals associated with increases in mammary gland tumors in at least one well-conducted animal study. Of these, 73 have been present in consumer products or as contaminants of food, 35 are air pollutants, 29 are produced at more than 1 million pounds per year in the United States, and 25 have involved occupational exposures to more than 5,000 women. Yet, despite the near certainty of widespread exposures to many of these chemicals, the findings have triggered virtually no regulatory or other policy response. Chemical or product manufacturers have not been required to examine the safety of their chemicals more closely, none of these chemicals has been removed from the marketplace because of breast cancer risk, and the overwhelming majority of chemicals identified as animal mammary carcinogens have never been included in an epidemiologic study of breast cancer. This urgently needs to change.

Laboratory and epidemiologic research, of course, must continue. Additional chemicals should be screened. Basic safety data are lacking for thousands of chemicals in commerce. Cancer assays should be modified to incorporate developmental exposures. The mammary gland should routinely be examined for structural alterations after developmental exposures. Epidemiologic studies need to be designed to account for early life exposures, although assessing past environmental exposures poses serious challenges.

But, this is not enough. Steps to reduce exposures to chemicals for which there is evidence of a link to breast cancer are urgently needed. Plausible evidence from animal or human studies should

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be sufficient to shift the burden of proof onto chemical or product manufacturers to demonstrate convincingly lack of harm from exposure. And if plausible evidence cannot be refuted in a reasonable period of time, suspect chemicals should be removed from commerce and replaced with safer alternatives. It is important to remember that even if the increased risk associated with a chemical exposure is relatively modest, the public health impact of reducing exposures would be profound when the exposed population is large.

For too long the complexity of breast cancer has kept us from taking steps to reduce or eliminate exposures to environmental chemicals plausibly woven into the causal web of this disease. Scientific uncertainty will always accompany our understanding of the origins of breast cancer and other complex diseases. This should not be an excuse to fail to act on the basis of what we know.

You can help create a healthier world for all of us by asking your Senators to support the Safe Chemicals Act, which would put common sense limits on toxic chemicals.

Dispatches from San Antonio Breast Cancer Symposium 2011

By Karuna Jaggar, Executive Director

Longtime BCAction members have read plenty about the annual San Antonio Breast Cancer Symposium (SABCS) over the years.

The most recent symposium in December was my first time at SABCS, and it lived up to the hype about the size of the conference and the scope of the science. SABCS is the largest international symposium on breast cancer, and the presenters and audience are an international mix of researchers and clinicians, from virtually every specialty.

The conference also lived up to its reputation for failing to place emphasis on women living with breast cancer. There was only one presentation I saw that included photographs of actual women; all the rest were full of diagrams of biological modeling and graphs of data. One scientist actually referred to women as "hosts" for the tumor. And in the conference newsletter on day one, not a word was said about why all these researchers and clinicians were presumably here—to save women's lives.

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But a strong and dedicated community of activists and advocates attend SABCS every year to ensure patient needs are represented, and to glean and translate relevant information for women living with the disease.

Breast cancer is a complex disease with complex causes. Over the dozen years I've been a patient advocate, I've seen dramatic changes in how a breast cancer diagnosis is described. Doctors used to emphasize staging that focused on the size and location of the tumor. Now, there is much more of a spotlight on receptor status and gene expression. In other words, when talking about breast cancer diagnosis and treatment, the emphasis has gone from how much cancer to include considerations of what type of cancer, reflecting fundamental shifts in how we think of the disease. The findings presented at SABCS spans the full sequence of research, from the lab, where scientists are working with petri dishes, to clinical trials, where women are taking newly developed drugs or new combinations of therapies.

The "basic science" presentations are anything but basic. Their focus is on experiments designed to lay a theoretical foundation for future studies. Many of the studies presented at SABCS are about developing an understanding of tumor biology, various mechanisms of action and other processes that are most readily observed in vials and petri dishes (otherwise known as "in vitro" studies). Other experiments then further test these hypotheses by repeating aspects of the studies in animals (also known as "in vivo" studies). Depending on results, this may then become the basis for study in humans, i.e. clinical trials.

The conference presentations on basic science, because of the very preliminary nature of the research, are not the place for advocates to learn about research that actually influences treatment, diagnosis, or prevention of breast cancer. No matter how good the basic science, it is not, to use one doctor's phrase, "ready for prime time."

It is the Phase III clinical trials that have the potential to actually produce meaningful change for women being treated for breast cancer. This year the main "practice- changing" developments focused on oncology and chemotherapy combinations rather than radiation or surgery.

Despite the excitement about the data from some long-anticipated trials presented at this year's SABCS, we are not seeing game-changing research. Instead, we have incremental benefits for particular subsets of women with specific tumor characteristics. This is just not enough. I am the first person to recognize that extending a woman's life by days and weeks is enormously meaningful and important to individual women and their loved ones in some situations. But we cannot settle for such small gains. We need dramatically more effective and less toxic treatments and nothing at SABCS pointed to those kinds of changes. That said, there were several practice-changing developments at this year's conference that I want to share with you.

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Two studies for women with metastatic disease found improvements of a few months' survival, in addition to what current treatments offer, through new drug combinations.

- For **metastatic HER2+ tumors**, the CLEOPATRA trial results showed that combining Herceptin (trastuzumab) with pertuzumab delayed progression of tumor growth by 6 additional months, with greatest benefit for ER- tumors. The study examined the effect of combining pertuzumab + trastuzumab in a double blind randomized study for HER2+ metastatic breast cancer in women who were previously untreated for the metastasis. In addition to the benefit to progression free survival, it was suggested there is corresponding benefits to overall survival, although the data is not yet conclusive. At BCAction we always demand that we keep sight of overall survival as the meaningful endpoint.
- For **HER2-, ER+ metastatic breast cancer**, the BOLERO-2 Phase III trial found a 4.1 month in progression free survival by adding Everolimus to Exemestane (Aromasin). This study was developed in order to address the issue of resistance to standard hormone therapies. The standard of care for metastatic hormone receptive breast cancer is to sequentially give single agent therapies, switching therapies when the disease progresses. Each subsequent therapy typically has a shorter window of efficacy and the goal of this study is to overcome resistance to endocrine therapy. The trial found that progression free survival improved by adding Everolimus, which was thought to inhibit other pathways when a tumor became resistant to endocrine therapies. There was a high rate of discontinuing treatment, the majority because of disease progression. The presenter suggested that the serious side effect profile of Everolimus be evaluated by patients in contrast to chemotherapy given that the alternative to hormone therapy is chemotherapy for metastatic disease. The presenter concluded Everolimus is the first agent to increase the efficacy of hormone therapy in patients with ER+, HER2- metastatic breast cancer. FDA approval of XX will likely be sought, as a way to overcome endocrine resistance and delay chemotherapy. It should be noted this is a very expensive drug.

Several trials looked at bisphosphonates, and the focus seemed to be on **ER+ early stage diagnosis**. Bisphosphonates prevent the loss of bone mass and strengthen the bone, and have been studied in metastatic breast cancer on the theory that they make the bone less hospitable for tumor growth. Bisphosphonates are being investigated for their role in (a) protecting bone health due to negative effects of endocrine therapy, (b) preventing bone metastasis and (c) improving disease free survival (and hopefully overall survival).

- Long term follow up of the Austrian Breast and Colorectal Cancer Study Group (ABSCG-12) found that the bisphosphonate, zoledronic acid (marketed by Novartis under Zomera or Zometa) may be a **new standard of care for premenopausal breast cancer patients with early stage ER+ tumors who are receiving hormone therapy** (tamoxifen or Arimidex). Regardless of which estrogen suppressor was used, the zoledronic acid group showed a

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28% reduction in recurrence with the treatment of this bisphospohonate. In addition to reducing recurrence, there was also a reduction in death. Overall survival was high in both groups and the study found that zoledronic acid improves overall survival compared with endocrine therapy alone. In summary, this study looked at patients with fairly good prognosis and met the primary and secondary endpoints of both disease free survival and overall survival. All women receiving zolodronic acid in the study saw these benefits; however, the age of the patient matters. The efficacy of this bisphosphonate is best in women over 40 with complete ovarian suppression, suggesting the need to deprive tumors of estrogen and bone growth factors.

- The ZO-FAST study found that long-term survival outcomes for postmenopausal women with ER+ early breast cancer benefited from adding zoledronic acid to letrozole. Similar to the ABCSG-12 trial, the Zo-FAST data indicate that zoledronic acid is most effective as an anticancer agent in a low-estrogen environment.

HER2 testing can produce different results for the same tumor based on different labs using different standards. Because it's a spectrum, there are questions of how to treat tumors that are HER2-equivocal, or HER2-borderline. Data presented at SABCS found that Herceptin works just as well in HER2-equivocal cases as it does in those that are strongly HER2-positive. Patients with borderline HER-2 status derive as much benefit from Herceptin after surgery as patients with strong HER-2 status.

For **ER+ tumor**s, GeparTrio Trial from Germany looked at whether there is greater benefit if neoadjuvant (i.e., pre-operative) chemotherapy is adjusted based on tumor response. This is called response-guided therapy. The somewhat surprising results of this trial appear to have sparked interest in further exploring pre-operative/ neoadjuvant chemotherapy, especially in hormone positive cancers for women who will benefit from chemotherapy. The study looked at patients who had received two cycles of TAC and evaluated the tumor response after 6 weeks. [Note: the trial occurred before Herceptin was widely available for HER2+ tumors.] "Tumor response" in this study was considered a 50% reduction in tumor size. The trial found that after 62 months of follow up—despite prior data showing no benefit to pathological free response—that there is benefit to this response guided therapy when it comes to both recurrence and death. This modified chemo treatment, based on tumor response, resulted in 30% reduction in recurrence and 20% reduction in deaths. Subgroup analysis showed that**almost all of this benefit was seen in hormone positive tumors**, whereas HER2+ and triple negative tumors did not benefit from response guided treatment.

Unfortunately, there were no major practice changing results announced that were relevant for **triple negative cancers**, which lack estrogen, progesterone, and HER2 receptors. Since triple negative breast cancers lack the presence of all three of these receptors, this subtype of breast

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cancer is more difficult to treat and more likely to recur. We need more to offer women with triple negative breast cancer.

An International Breast Cancer Study Group reinforced earlier studies that found **no benefit of full axillary dissection**—that is removal of all lymph nodes —for women with minimal sentinel micrometastases. Since the early days of the radical mastectomy, the rule of thumb for surgery has been "more is better," and many surgeons have considered axillary dissection the gold standard for patients with micrometastases in the sentinel node. There is growing consensus that axillary dissection of lymph nodes appears to be unnecessary and represents overtreatment for many women. There was a strong plea from the presenters and Dr. Laura Esserman of UCSF who was seated in the audience that given the serious side effects of axillary dissection—including lymphedema and neuropathy—**the standard of care should be to not do axillary dissection when there is minimal sentinel node involvement**.

Partial radiation for breast cancer—a week of radiation to part of the breast instead of longer treatment to all of it—though **brachytherapy** appears to result in higher recurrent with 4% of brachytherapy patients needing surgery to remove the breast compared to just 2% of those given traditional radiation. Despite the hope that less radiation for a shorter duration would produce fewer side effects, the brachytherapy patients also reported more infections, hospitalization, broken ribs and breast pain.

What other lessons did we learn?

- With current cut backs to government funding, Pharma funding increasingly drives and influences breast cancer research. This is not an acceptable alternative. We need increased government funding to ensure independent research and we need to not rely on Pharma funded research to meet our needs.
- Several researchers made a plea for tissue samples and a national bio-specimen collection, as a standard part of future studies. This would require significant infrastructure investment and planning as well as addressing medical privacy issues.
- Patient-reported outcomes need more attention because, as we've always argued *they matter.* We need to ask patients directly and include their response regarding side effects if we want to accurately understand women's experiences with treatment. It's no surprise side effects are correlated to treatment "adherence"— when side effects are too bad, women stop taking the drugs. When women are asked about side effects, there are always more side effects than clinicians report. Yet, side effects are tremendously important because they negatively affect health-related quality of life.
- Many researchers and clinicians continue to be hopeful about the promise of Avastin, despite lack of evidence that the drug benefits patients. The official SABCS Newsletter 3,

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placed on every seat each morning, opened with a piece titled "Understanding Results from AVEREL as a Positive Way Forward" despite the fact that AVAREL was a negative study–it did not reach its endpoints. AVAREL was a randomized Phase III trial that looked at Avastin in combination with Hercptin and docetaxil as a treatment for metastatic HER2+ breast cancer. The investigators did not find a statistically significant reduction in progression free survival after an average of 26 months. However, after engaging an independent review committee to re-evaluate (and re-classify) the data, there was a statistically significant finding of a 2.9 month gain in progression free survival with the re-analyzed data.

- Even though we are learning more about the different characteristics of different breast cancers, tens of thousands of women continue to be overtreated each year because we just don't know who will benefit from which treatment and so, to be on the "safe side" (which may not be all that safe), we subject all women within a particular diagnostic profile to the same treatment. It was interesting to hear a number of researchers and clinicians talk about the issue of overtreatment in various contexts, noting that after many years of tying to help women by adding therapies, for some women it may be time to think about less treatment.

In Memoriam: Rachel Cheetham Moro

We were deeply saddened by the loss of Rachel Cheetham Moro, who died February 6, 2012, of metastatic breast cancer. Rachel was a "virtual colleague" for us at Breast Cancer Action, and we mourn the loss of a fierce writer, breast cancer activist, and friend.

Rachel's powerful writing and activism at The Cancer Culture Chronicles was a resource and inspiration for many. Rachel dissected with incisiveness and humor the "pink ribbon razzmatazz" culture around breast cancer and advocated relentlessly for a sea change in how we understand and address the breast cancer epidemic.

Very little research funding goes to metastatic breast cancer, which is what killed Rachel and ultimately kills most women who die of breast cancer. We know far too little about how to stop this disease from developing in the first place let alone how to stop it once it spreads. Our screening tools are imperfect. Our conventional treatments are expensive and toxic. As Rachel reminded us time and time again, the breast cancer status quo covers these ugly truths with pink ribbon

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paraphernalia. If you've not read her powerful essay "The Dark Side of Pink Awareness," you can read it here.
Rachel's mantra was, "It's time to move beyond pink ribbons and messages of 'breast cancer awareness' and start agitating for real and meaningful action in the fight to eradicate this disease for good." We could not agree more.

We feel deeply honored and proud to have counted Rachel among our friends and continue to be inspired by her. We will continue to carry Rachel's torch in moving beyond the "pink razzmatazz" to systemic change that will end this terrible epidemic

You can read more testimonies to Rachel's advocacy and writing from other breast cancer activists and share your thoughts here.

And don't miss this moving video made by two other fierce breast cancer activists,Sarah Horton and Gayle Sulik, about Rachel's life and work.

Health Is Not Just Healthcare

By Sahru Keiser, BCAction Program Associate of Education and Mobilization

President Barack Obama's Patient Protection and Affordable Care Act is an important step in eliminating health disparities, but this legislation does not go far enough. At Breast Cancer Action, we've always been committed to the development and implementation of legislative solutions that will insure universal access to quality health care for all people living in the United States. The Affordable Care Act is not that legislation.

But the legislation, which will deliver care to over 30 million uninsured Americans, is without a doubt ground-breaking. The legislation, which goes into full effect by 2014, will provide insurance for more than half of the 49.1 million nonelderly people in the United States who were without health insurance in 2010. There are some facts we know about the faces of the uninsured in this country. She or he is a young adult of color from a low-income family in which there is at least one working adult. Almost half of the uninsured have a chronic disease like cancer. And the lack of adequate health insurance means patients are less likely to receive adequate, timely care.

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The data continues to show that people of color have worse health outcomes than their white counterparts even among those who have health insurance. Gaining access to health care and medical treatment is an important step to better health, but access alone will not eliminate the widespread health inequities that have been persistent for decades. Equal access to education about ways to take better care of yourself is not a silver bullet that ensures good health, but neither is leveling access to health care.

Inequities in breast cancer incidence and outcomes are well documented but not well understood and are often inadequately addressed. We know that while white women have a higher incidence of breast cancer, African American and Latina women are more likely to die from the disease. A complex interplay of health care and social factors can explain these differences in breast cancer outcomes.

We know that only a relatively small percentage of deaths could be avoided, about 10–15 percent, with the availability of quality medical care. Current health care takes as its primary focus the goal of reducing the severity of disease that already exists, yet addressing the social factors of where we live, work, and play can potentially prevent disease from occurring in the first place.
These social factors, also known as the social determinants of health, are risk factors that are determined by the social conditions in which we live and work and in which we make choices about how to live our lives. Prevailing narratives about individual responsibility and smart consumer choices continue to miss the mark because they fail to take into consideration a simple reality that informs how people make health decisions: "The choices we make are shaped by the choices we have."

The physical and social environments in which we live and encounter limit or expand our options for improving health and avoiding disease. This understanding should be reflected in policies aimed at both personal and community responsibility to truly change the inequities we see in disease incidence and outcome.

Reynolds, et al., notes, "Geographic location is one of the strongest predictors of breast cancer incidence." Geographic concentrations of poverty, including fewer options for high-quality education, fewer job opportunities, substandard housing, racially and economically segregated neighborhoods, and a lack of community and social support are all critical factors in determining actual standards of health. Unsurprisingly, these are all characteristics also of an unhealthy neighborhood and unhealthy neighborhoods are disproportionally poor communities of color.

Compounding this burden, early childhood experiences and social disadvantage have long-term effects on health outcomes through one's life course. Social disadvantage may not last a lifetime, but research shows that cumulative effects at critical windows of development — in utero, early

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childhood, and adolescence — can affect health outcomes and potential for increased disease development over one's life course. For example, lead poisoning in early childhood, from exposures to lead-based paint in substandard housing, can cause permanent neurological damage.

Simply advocating for greater access to health care will not "fix" poor health outcomes — communities also face barriers once they have access to health care. Language barriers, low health literacy, discrimination, and a long history of medical mistreatment are just some of the barriers to receiving high-quality health care.

- Language/Cultural Barriers: Providers are not prepared to serve the multicultural and multilingual society that has been evolving over the last century. Nearly 14 million Americans are not proficient in English, and population growth in the United States is fastest among minorities as a whole. The burden of education lies on providers to provide. In this case, that means offering culturally appropriate medical care with interpretation services if necessary.
- Health Literacy: Another obstacle to overcome that many people face once they are able to access health care (provided they have adequate health insurance), is knowing how to use and access medical services. Not understanding how to navigate the insurance and medical system results in patients unknowingly refusing recommended services, not following treatment protocols, all of which often culminates in delays in seeking care.
- Racism/Discrimination: Communities of color continue to face prejudice and stereotyping by health care providers. There is limited access to and availability of providers who are culturally sensitive and able to understand and relate to cultural beliefs and traditions that are not their own. Currently, there are only three oncologists in the United States who are of Native American descent and 184 who are of African American descent. A lack of physicians who are not able to create a culturally sensitive space can lead to lower quality medical care and decreased provider-patient trust and communication.
- Mistrust of medical community: There is a long history of abuses in medicine via the withholding of medications to study the progression of untreated diseases, such as the Tuskegee syphilis study, involuntary sterilization of women of color, and unauthorized research of blood samples of Native American tribes. This history of exploitation and medical mistreatment and the resulting scars that remain have created a legacy of mistrust. Poorer communities, predominately communities of color, have experienced numerous cases of medical mistreatment as recently as 1990. Studies show that trust in medical providers establishes a consistent and stable doctor-patient relationship which in turn is an important in step in accessing care. The importance of trust works in both directions as the possibility that a provider might disengage with a patient who is mistrustful and noncompliant can potentially lead to providers who are less likely to provide more vigorous services.

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A combination of obstacles faced in both the social context of how we live and the barriers to high-quality medical care once we have access to health care result in the inequities we see in the health outcomes of communities of color. If we want to impact both the prevention and the severity of disease occurrence, we need to focus on interventions outside the health sector, which are more likely to have an impact on disease prevention, and on health care policies, which will have a stronger effect on the severity of disease.

We all deserve an equal opportunity to choices that lead to good health. It is time to dispel the myth that health is something we get at the doctor's office. Health begins in our neighborhoods, schools, jobs; it begins in the air we breathe and the water we drink.

We need policies that address both the social determinants of health — the social factors that influence where we live, work and play — and the barriers that people face when accessing health care.

We have come a long way in understanding the ways in which where we live, work, and play affect our health, but our work is far from done. Our understanding of these social factors has not been translated into programs that eliminate health inequities. We need strategic partnerships and collaborations across disciplines that will include health and health equity in all policy, from land use and city planning to economic development and beyond.

This article is based on a BCAction factsheet titled "Health Is Not Just Health Care," available soon here.

Charlotte Didn't Sell Out. Neither Should We.

By Robyn Stoetzel, R.N., BCAction member

Does the name Charlotte Haley sound familiar to you? Until recently, I had no idea who she was, despite being a former oncology nurse. I've spent my life alongside women diagnosed with breast cancer. And yet Charlotte's story was completely unknown to me.

Charlotte Haley should be one of the most famous women in the world. Everyone touched by breast cancer should know her story.

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Charlotte created a peach ribbon in 1990 that she attached to postcards asserting "The National Cancer Institute's annual budget is $1.8 billion, only 5 percent goes for cancer prevention. Help us wake up legislators and America by wearing this ribbon."

Charlotte inspired me. Not just because she took action and raised her voice against a giant like the NCI but because she refused to sell out when Self magazine and Estee Lauder wanted to use her peach ribbon as a promotional tool during Breast Cancer Awareness Month.
She refused because she wanted to motivate people like you and me to take action to stop breast cancer before it starts. She recognized that they had a different agenda, one that was about marketing cosmetics, not preventing breast cancer. Unable to get Charlotte's permission, they found another color for the ribbon, a color that was "soothing, comforting, quieting"—all the things breast cancer is not.

The story of how the peach ribbon turned pink is one every woman concerned about ending the breast cancer epidemic should know. And it's the reason you should read it for yourself.

How did I find out about Charlotte Haley? I downloaded a Think Before You Pink® Toolkit that inspired me to do more to address and end this epidemic.
If the story of Charlotte Haley shocks you, be prepared for a lot more shocking information when you download your own Think Before You Pink Toolkit here for free.
And the Think Before You Pink Toolkit isn't simply full of shocking truths. It is filled with ways each of us can take action to address and end this breast cancer epidemic. It's full of questions to ask and answers to give. It saved me hours of research and provided an alternative viewpoint about breast cancer I wasn't getting anywhere else.

Charlotte Haley took action because she wanted to protect her family and close friends—too many of whom were being diagnosed with breast cancer.

Take up Charlotte Haley's mantle. Download your free Think Before You Pink Toolkit by visiting http://www.bcaction.org/toolkit.

Together we can take back this breast cancer movement and make it about women's health and putting patients first rather than shopping and corporate profits.

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Program Update

By Kim Irish, Program Manager

We've had a busy quarter since the last issue of *The Source*. Our monthly webinars continue to generate strong attendance so we'll be bringing more of those to you over the coming months. Thank you to the thousands of you who have downloaded BCAction's Think Before You Pink® Toolkit. Our hope with this toolkit is to put a tool for significant change into the hands of activists across the country so we can change the status quo in breast cancer one pinkwasher at a time. And finally, Komen's decision to defund and then refund Planned Parenthood outraged us to action. We were inspired by the women's health activists who demanded Komen put women's health before corporate and political agendas. These demonstrations of individual activism means one thing: collectively we are creating change.

Educating and Empowering Women Affected by Breast Cancer

Our monthly webinar series is a great way for people living anywhere in the United States (or even abroad!) to plug into the latest news and analysis and connect with other activists working for change. We co-hosted a webinar in November with staff from Environmental Working Group and the Campaign for Safe Cosmetics:Toxic Cosmetics: What Consumers Don't Know About Their Beauty Products and What You Can Do About It. We took a hard look at the problems with our current cosmetics regulatory system, discussed who exactly is put at risk by toxins in cosmetics, and highlighted ways individuals can take action to change the current system that permits harmful chemicals into our personal care products.

In January, the focus of our webinar was the IOM Report on Breast Cancer and the Environment, which was released during the San Antonio Breast Cancer Symposium in December. The webinar, A Briefing for Advocates: The IOM's New Report on Breast Cancer and the Environment, was presented by BCAction's Executive Director Karuna Jaggar and staff from the Silent Spring Institute.

And finally, in February, Program Associate of Education & Mobilization Sahru Keiser, Think Before You Pink activist Robyn Steotzel and I hosted a webinar called Turning Knowledge Into Action: The Think Before You Pink® Toolkit. We walked attendees through all the various activist resources, educational tools, and campaign ideas in the toolkit. And Robyn took us through all the ways she has used the toolkit to create her own campaigns to end pinkwashing.

If you've missed any of these or other previous webinars, you can find past topics, descriptions, and watch recordings here. And please, visit the same website page to sign up for future webinars, too.

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We've been receiving pretty strong feedback on the webinars. I'd like to offer some samples in the hope that many of you will be inspired to join us for future sessions:

"This was my first BCAction webinar which I found very interesting, informative and educational especially since I am a health care provider and a breast cancer survivor."

"Great webinar! Easy to access, speakers were very clear and concise. Thank you and keep up the extraordinary work that you do."

"It was great. Well rounded. Informative. Organized. Included key resources."

BCAction provides information about breast cancer to anyone who needs it. Contact our Resource Liaison, Zoe Christopher, at info@bcaction.org or call toll free at 877-2STOPBC with questions you have. In the past few months, Zoe has responded to questions about the quality of breast cancer treatment for incarcerated women, treatment options for elders, side effects of aromatase inhibitors, the IOM report on breast cancer and the environment, breast implants, and ductal carcinoma in situ (DCIS).

Organizing and Training Advocates

Our new Think Before You Pink® Toolkit is proving to be a great resource for activists. The toolkit is divided into three sections: *Learn* offers you an insider's look at pink ribbon marketing and the politics of breast cancer; *Share* provides you with a list of critical questions to ask about pink products and ways you can engage friends and loved ones when you are asked to sponsor them in a breast cancer walk or run; and the *Act* section contains specific ways to take action that will move us closer to really addressing and ending the breast cancer epidemic.
Nearly 3,000 of you expressed your outrage when Susan G. Komen for the Cure allowed politics to come before women's health when they decided to pull funding for Planned Parenthood's vital healthcare services. The result of your advocacy and that of other women's health activists? Komen restored the funding to Planned Parenthood. It was a victory, and showed us what is possible when we take action together.

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Demanding Regulatory and Legal Reform

BCAction is a plaintiff in the lawsuit challenging Myriad Genetics' patent on the "breast cancer genes," BRCA1 and BRCA2. The latest news on this comes from our attorneys at the ACLU and the Public Patent Foundation, who petitioned the U.S. Supreme Court in December to hear our case. In early March, we attended a public hearing hosted by the U.S. Patent & Trademark Office and provided testimony about the harm gene patents do to women. You can submit your comments about gene patents and genetic testing directly to the U.S. Patent and Trademark Office so women's health is not left out of the picture.

We continue to closely monitor legislative regulations that will bring the broad systemic change that plays an important role in addressing and ending this epidemic. In December, we signed on in support of a number of pieces of legislation to that end, including Congressman Markey's petition to the FDA to ban bisphenol A (or BPA, which is a synthetic estrogen used to harden polycarbonate plastics and epoxy resin) from infant formula and baby food packaging, canned food, and reusable food containers.

In January, we opposed the FDA's Draft Guidance for Industry and Food and Drug Administration Staff on the de novo classification process (which is a regulatory pathway for some low- to moderate-risk medical devices that are not comparable to a legally marketed device) because the process does not require proof of the safety or effectiveness standards for these devices, and thus doesn't improve patient safety.

In November, we signed on in support of a letter to members of the House Energy and Commerce Committee and the Senate Committee on Health, Education, Labor and Pensions urging them to support policy that would give the FDA authority to recall dangerous drugs, improve FDA inspections and oversight of high risk sites, so we can continue to improve consumer safety. We also supported the federal Safety of Untested and New Devices (SOUND) Act of 2012, aimed to protect people from avoidable harms caused by unsafe devices that should never have been cleared for sale in the first place.

Your involvement is critical to the success of all of the efforts mentioned above.Sign up for BCAction e-alerts to learn about breaking breast cancer news, our advocacy efforts, and more. Join our monthly webinars. Download your copy of the Think Before You Pink Toolkit.

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Save the Date! Private Pink Ribbons, Inc. Preview

Special private preview of *Pink Ribbons Inc*.

Thursday, May 31st
San Francisco, CA

Visit http://www.bcaction.org/pinkribbonsinc to get your ticket.

Join us for an evening of inspiration, motivation, and a movie that is sure to both enrage and entertain. This movie is a potential game-changer, showing just how much the shiny pink status quo has cost us—and how little we've gained from it. As BCAction's former executive director Barbara Brenner says in*Pink Ribbons, Inc*. , "If people actually knew what was happening, they would be really pissed off."

The film is based on Samantha King's brilliant book of the same name, *Pink Ribbons, Inc*. which pulls back the pink curtain on why we aren't making the progress we need to end the breast cancer epidemic. It's a curtain Breast Cancer Action has been tugging on for over a decade through our Think Before You Pink® campaign, where we encourage people to ask critical questions about breast cancer fundraising. We are thrilled to see this message go mainstream.

Special Thanks: Spring 2012

We could not do this work without the support of so many members and volunteers. A huge thanks to:

Janet Ackerman, Research Assistant at Silent Spring Institute for your participation in our January webinar and your willingness to step in and provide important information about what it means to study environmental health.

Jonathan Darr, for your creative fundraising for—and fierce commitment to—women's health organizations, including Breast Cancer Action.

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Mia Davis, formerly the Organizing Director for the Campaign for Safe Cosmetics for your participation in our Nov webinar on Toxic Cosmetics and your continued dedication to protecting the health and safety of all of us.

Yvonne Day-Rodriguez (designer) for your beautiful design work.

Catherine DeLorey, for co-hosting the Boston houseparty and for all you continue to bring to BCaction.

Jeff Harris, CEO Talkwheel, for donating and making this service possible for BCAction.

Majorie Marjorie Kagawa-Singer, Nancy Krieger, Catherine Thomsen, Sora Park Tanjasiri, Scarlett Lin Gomez, Linda Burhansstipanov and Dominique Apollon for their willingness to dedicate time and energy in finding resources for the development of our inequities factsheet.

Joan Kelley and Cynthia Hall, for so skillfully and enthusiastically staffing BCAction's table at the San Antonio Breast Cancer Symposium.

Alli Knox, BCAction intern for your dedication and work in helping us develop a list of potential partners around the country.

Nneka Leiba, Senior Analyst for Environmental Working Group for your invaluable expertise on the chemicals in beauty care products and your wonderful presentation on our Nov webinar on Toxic Cosmetics.

Qianyi Li (program intern) – for your conscientious hard work on fact sheets and campaign work!

Development volunteers Mara Meaney-Ervin and Devon McKnight for all their hard work,

Manuel Carrasco Moñino, of Talkwheel, for your patience and expertise in the installation.

Judy Norsigian, for hosting the Boston houseparty and for lending your time and wisdom to our Board nominations committee.

Andy Rivera, for your immense skill and infinite patients in designing our Annual Summary.

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Ruthann Rudel, Director of Research at Silent Spring Institute for your participation in our Jan webinar and insight on how chemical exposures may influence breast cancer risk.

Robyn Stoetzel, Breast Cancer Action member extraordinaire, for your passion and dedication demanding answers to truly preventing breast cancer. Also for co-presenting in our Feb webinar, speaking at the Pink Ribbons Inc. screening in Chicago and writing a powerful blog for our Think Before You Pink website.

Linda Thai, for over two years of invaluable support to our development department. We will miss seeing you every week!

Natalie Waugh, for your strategic advice and counsel.

Poonam Whabi, for your helpfulness, expertise and flexibility in always coming to our aid.

Jane Zones, for continuing to bring your wisdom and experience to BCAction by serving on the nominations committee.

Thank you to the **8th Annual Billie Gardner Loulan Memorial Luncheon Event Steering Committee** for your hard work and dedication: Donna Andrighetto, Diana Bergeson, Linda Benvento, Donna Carano, Christina Feeny, JoAnn Loulan, Jayne Mordell, Amber Raimes, Michelle Rapp, Linda Rigas, Valerie Russell, Angela Schillace, Kris Schmidt, Julia Shaw, Bonnie Sterngold, and Lisa Troedson.

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DONATIONS IN HONOR

BCAction gratefully acknowledges donations made in honor of the following individuals between November 28, 2011 and March 21, 2012.

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from Beth Abels

All of Us
from Anonymous
from Lynda Hillman

Jeremy Manson & Amber Kerr
from Shari Mayer

Charlotte, Kathy and Mary Ann
from Margo L. Arcanin

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from Brett Anderson

Rita Arditti
from Women's Community Cancer Project

Abigail Arons
from Elissa and Daniel Arons

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from Karen Soroca

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from Anonymous
from Anonymous
from Anonymous
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from Joseph S. Brenner
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from Marilyn Milkman and Adam Gordon
from Kelly Moran
from Judith Norsigian
from Pauli Ojea
from Judith A. Patrick
from Nancy Pemberton and Jeff Parker
from Elizabeth Plapinger and John Berger
from Elizabeth Pritzker
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from Heather and Kitt Sawitsky
from Herva Lenore Schwartz

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from Jane Sprague Zones

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from Gerald Epstein and Fran Deutsch
from Irma D. Herrera and Mark D. Levine
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from Diana Bergeson

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from Anonymous

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from Glenda Sharp

Lori Leigh Gielghem
from Karen Merritt

Trudy Goldau
from Sharon Goldau

Gayle Goldman
from Jessica and Benjamin Rosenberg

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from Nickie Hilbert

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from Coral J. Fry

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from Alison and Phil Braverman

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from Lynne Cary

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from Trinidad Madrigal

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from Christine Collins

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Dory Meier
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Irene Monroe
from Anonymous

Rosario Morales
from Women's Community Cancer Project

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from Karen Strauss

Tara Muir
from Tracy Grinstead-Everly

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Olivia Munks
from Brenda Munks

My Mom
from Michelle Redstone

My Sister
from Anonymous

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from Erika Tingey

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Nina Sherak
from Gladys Sherak

Jocie Sobieraj
from Anonymous

Sandra Steingraber
from Laurie Salen

Kyra Subbotin
from Laura Enriquez

Those Living With and Having Lived With Breast Cancer and the Family and Friends Who Support and Love Them
from Linda L. Gustafson

Too Many Women to List, Including Both Our Mothers
from David Lucal and Deborah Chassler

Mrs. Heather Thomason
from Martha Saltzman

Marcella Trujillo Martinez
from Virginia Franco

Lynne Walker
from Ellen Leopold

Martha Walters
from Stephanie Schus

Jessie Weber
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from Phyllis Schoenwald

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from Anonymous

Beverly Ziegler
from Julia E. Tower

Marilyn Zivian
from Fran and Bud Johns

Linda Zumwalt
from Anonymous

Patti Zussman's Birthday
from Lois and Milton Zussman

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DONATIONS IN MEMORY

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from Margaret Rossoff

All Lost to Cancer
from Michelle Redstone

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from the Geology Department
from Jennifer and Michael Harich
from the Faculty and Staff of Hopewell High School
from Jennifer Wood

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from Victoria Gray

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Beth Haas
from Varya Simpson

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Hannah Wilke
from Marsie Scharlatt

Mary Williams
from Carol Ann Williams and Roderic Johnson

LaDonna Wills
from Ginger Anderson

Jackie Winnow
from Carla Schick and Diana Curiel

Noah Wolfson
from Alice J. Wolfson

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